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## PE1404/Q

Anne Peat, Clerk to the Public Petitions Committee, Room T3.40, The Scottish Parliament, Edinburgh, EH99 1SP Date: 31 January 2013

Your Ref:

Our Ref: AL/jc/0332

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Dear Ms Peat,

## **Consideration of Petition PE1404**

Further to your letter of 11.1.13, the following provides a summary of NHS Lanarkshire's position in relation to the Scottish Government target for the provision of insulin pumps to those under 18 years of age.

NHS Lanarkshire is fully supportive of the government's insulin pump targets and has worked extremely hard to maximize the number of people receiving CSII therapy. When CEL 4 was published, we had an established adult pump service, but did not have an equivalent for those under 18 years of age. It was agreed at the outset that it was inappropriate for the adult pump service to deliver CSII therapy to children, so a paediatric service had to be set up. This involved:

- Initial training for medical, nursing and dietetic staff
- Shadowing adult staff at insulin pump clinics
- Reviewing the medical history of all Lanarkshire children with diabetes to determine their suitability for pump initiation
- Liaising with children and their parents to identify 99 children under 18 years of age (the CEL 4 target number) who wished to start on a pump

Following publication of CEL 4, NHS Lanarkshire developed an action plan and estimated that by March 2013 it would both establish a paediatric pump service and start 32 children on an insulin pump. As of 8<sup>th</sup> February, NHS Lanarkshire has exceeded its action plan targets, as shown below.

|                        | Action Plan         | Position as of      | <b>Expected by</b>  |
|------------------------|---------------------|---------------------|---------------------|
|                        | target              | 8.2.13              | 31.3.13             |
| Paediatric pump        | Establish new       | Service fully       | Full service        |
| service                | service             | established         | continues           |
| Children under 16      | Start 10 children   | NHS Lanarkshire     | NHS Lanarkshire     |
| years on insulin pump  |                     | started 10 children | started 13 children |
|                        |                     | NHS GG&C            | NHS GG&C            |
|                        |                     | started 5 children  | started 8 children  |
| Young people aged 16   | Start 22 young      | 3 young people      | 13 young people     |
| and 17 on insulin pump | people              | started             | started             |
| Adults 18 years and    | Start additional 16 | 20 additional       | No further adult    |
| over on insulin pump   | adults              | adults started      | pump starts         |

The total number of Lanarkshire children currently on insulin pumps is 18, and this number will rise to 34 by March 2013, which is two more than originally planned. NHS Lanarkshire's paediatric service now feels confident that the target of 99 children on pumps can be achieved by March 2015 instead of March 2016, as originally planned, starting 33 in each of the next two years. Fewer 16 and 17 year olds than hoped have expressed an interest in insulin pump therapy, despite being written to by the Consultants running the clinics. In addition, many of those who wish a pump have asked for the start to be delayed until they finish their exams.

Our current position represents considerably more insulin pump starts than can usually be expected from a new paediatric pump service and the staff involved in achieving this level of success have worked tirelessly. Any attempt to start more children on insulin pump therapy would have put the children themselves at considerable clinical risk since the staff would not have been fully trained and could not have ensured safe use of the technology. Children require considerably more support from the clinical team than adults.

During 2012/13 NHS Lanarkshire's adult pump service has increased the number of people 18 years and over on insulin pumps from 56 to 76, which is four more than projected in our Action Plan. NHS Lanarkshire also runs Dose Adjustment for Normal Eating (DAFNE) education courses for patients across its three acute hospitals which enables people to optimally manage their diabetes.

NHS Lanarkshire is confident that it will achieve a reasonable proportion of the original ministerial targets for children and adults by March 2013 and the full targets by March 2015, but we would ask the committee to recognize the considerable amount of work that has gone into establishing the paediatric service from scratch and achieving a higher number of pump starts than projected in our Action Plan. The ministerial target was very helpful in focusing minds and funding the pumps has been a good catalyst for progress.

NHS Lanarkshire would also like to draw attention to two confounding issues:

A fairly high number of Lanarkshire children (n=16) have refused outright to have an
insulin pump. This is mainly because of body image issues, although the appetite for
CSII therapy is expected to increase once the service becomes more firmly established

• Local schools have highlighted that they are not insured to be involved in the care of pupils on insulin pumps and their willingness to assist varies on a school-by-school basis. We are in discussion with local authority colleagues to find a way forward, as lack of co-operation may detract from children functioning well on CSII therapy. Scottish Government may have a view on this issue

Yours sincerely

## **Alan Lawrie**

Interim Director of Acute Services